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Physical health problems in people with psychosis: the issue for informal carers

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Running head: Carers and physical health

Abstract:

Background: Reduced life expectancies are recorded in adults with psychotic disorders. Informal carers play key roles in improving illness outcomes for patients, including significantly reducing rates of relapse and hospitalisation. There is, however, a dearth of literature detailing carers' perspectives on physical health problems in the relatives they care for and their implications for those in the caregiving role. The study sought to explore carers' subjective experiences of supporting a relative with psychosis and physical health problems.

Methods: Carers of adults with psychosis were interviewed individually, or as part of a group, about physical health problems in the relatives they care for.

Results: Five key themes were identified from the interviews that reflected: (i) ubiquity of physical health problems in psychosis (ii) gaps in service provision for those living with mental and physical health problems, (iii) carers' role in responding to service gaps (iv) difficult conversations and, (v) impact on carer health.

Conclusions: Service initiatives that are designed to improve patient physical health in psychosis should not overlook the role that informal carers might have in supporting this process. The implications that patient physical health problems present for carer wellbeing and the quality of the caregiving relationship in psychosis deserve further investigation.

Keywords:

Psychosis, Carers, Severe Mental Illness, Physical Health

Background

Poor mortality rates in adults living with psychotic disorders are widely documented (Hayes, Marston, Walters, King, & Osborn, 2017; Hjorthøj, Stürup, McGrath, & Nordent, 2017) and current evidence suggest a 15-20 year reduced life expectancy in patient groups with severe mental health disorders such as psychosis, compared to the general population (Hayes, et al., 2017; Nielsen, Uggerby, Jensen, & McGrath, 2013; Dutta, Murray, Allargyce, Jone, & Boydell, 2011). The reduced mortality rates and higher morbidity are attributable to several factors including an excess of physical health conditions such as cardiovascular disease (Laursen, Nordentoft, & Mortensen, 2014), diabetes (Vancampfort, et al., 2016), metabolic syndrome (Vancampfort, et al., 2015), and respiratory illness (Filik, Purdy, Gale, & Gerrett, 2006), which are considered largely preventable with modifiable risk factors. The iatrogenic effects of pharmacological treatments (e.g. appetite changes, weight gain, lipid abnormalities) (Ventriglio, Gentile, Stella, & Bellomo, 2015; Rummel-Kluge, et al., 2010), in association with poorer lifestyle habits (e.g. sedentariness, smoking, poor nutrition) (Stubbs, et al., 2017; Cook, Wayne, Kafali, Liu, Su, & Flores, 2014) and reduced access to services, optimal treatments and timely interventions, are also key factors in yielding poorer health outcomes and mortality in people with psychosis (Moore, Shiers, Daly, Mitchell, & Gaughran, 2015; Newcomer & Hennekens, 2007).

Many adults living with psychotic disorders are closely supported by informal caregiving relationships and input from carers can play a significant role in optimising positive illness outcomes. Thus, support from informal carers is associated with facilitating significant reductions in levels of patient relapse and hospitalisation (Norman, Lewis, & Marshall, 2005) and increasing patient engagement in services and prescribed treatments (Stowkowy, Addington, Liu, Hollowell, & Addington, 2012). More recently, evidence suggests that patients with carer support compared to peers without, can also achieve better rates of mortality (Reininghaus, et al, 2015; Ran, et al., 2016).

While initiatives to improve physical health outcomes in adults with psychosis remain an increasing priority for health providers (National Institute for Health and Care Excellence [NICE], 2014; Royal College of Psychiatrists, 2013); hitherto, these efforts have predominately focused on upskilling clinical staff in problem identification, early and preventative interventions, alongside strategies to promote and incentivise healthy lifestyle changes in patient groups (Gaughran, et al., 2013; Alvarez-Jimenez, et al., 2010; Bailey, Gerada, Lester, & Shiers, 2012). Despite the important contribution of caregiving relationships to facilitating positive outcomes for patients with psychosis, and a call for greater consideration of carers in promoting physical healthcare interventions for patients (Fung & Gardner-Sood, 2012; Happell, Platania-Phung, Gaskin, & Stanton, 2016), carer perspectives on physical health issues in patient groups have been largely ignored by service providers and policy makers. Achieving a better understanding of patient physical health in psychosis, through the perspective of those who are closest to them, may offer a helpful pathway to improving physical health outcomes in people with psychosis.

Aims

In a sample of informal carers of adults with psychosis, this study sought to examine carer experiences of physical health issues in their relative and links with the caregiving relationship. The study was embedded within the broad methodological framework of qualitative exploratory research, which lends itself well to the study of areas that lack a literature (Stebbens, 2001).

Methods

The project was approved by the National Health Service (NHS) Trust audit and evaluation committee (reference number: PSYAUD15/10). It employed a cross-sectional design using focus

groups and individual semi-structured interviews. Participants were carers ~~caregivers~~ of adults with psychotic disorders and recruited from two NHS carer support groups. One group was open to carers of patients being treated in an adult community mental health psychosis service, while the second group was open to carers of patients who were or had been previously been inpatients of a specialist ward for people with treatment resistant psychosis. Potential participants were informed about the study through a team newsletter and poster. No data were collected on any carers who were aware of the project but opted to not participate. Participants were invited to take part in the focus group. They were also given the option of completing an individual interview if they wished to be involved, but were unable to attend the group interview.

The individual and group based interviews were completed in NHS settings. The interview protocol was developed by the authors and informed by a review of the current literature spanning mental health caregiving experiences and patient physical health, and consultation with carers. The schedule comprised questions that were intentionally designed to be broad and facilitative of carers' personal accounts and perspectives. The questions focused on carers' experiences of physical health issues faced by the relative they care for, how they relate and interact with their caregiving role, and how they cope. No pilot interviews were undertaken before commencing the interviews.

The focus groups were facilitated by the first two authors, a postgraduate and graduate psychologist, respectively. The two individual interviews were facilitated by the postgraduate psychologist. The first author was employed in one of the recruiting services, but unknown to participants, the second author had no relationship with either service. Both researchers had clinical and research experience of psychosis, working with carers and undertaking qualitative methods of research. Participants were informed about who the researchers were, their academic and clinical interest in working with issues related to psychosis, and what their role would be in facilitating the focus groups and interviews. The focus groups lasted approximately 70 minutes and the individual interviews ran for approximately 45

minutes. All interviews were digitally recorded. Participants were compensated ten English pounds for their time. No repeat interviews were undertaken with participants.

Analyses

The recorded interviews were transcribed verbatim by the first two authors. Transcripts were not returned to participants for comments. The transcripts were thematically analysed, in accordance with principles from Braun and Clarke (2006). All themes were derived from the data. All data collection and coding were undertaken independently. The analysis commenced with a familiarisation process comprising repeated reading of the transcripts. Following detailed study of each line of text, the primary codes were extracted, which were initially organised around *prima facie* similarities and differences and then subsequently into potential categories. After the completion of coding, the researchers held regular discussions to reach consensus on the identified themes.

Results

Sixteen carers participants participated in the study. Two carers ~~caregivers~~ were participated in individual interviews and the remainder attended one of two focus groups that were held. No consenting participants dropped out of the study. In accordance with accepted principles (Bowen 2008), the researchers felt that data saturation had been achieved with the recruited sample.

The sample age ranged between 35 to 79 years, with an uneven ~~equal~~ split between male and female participants with females representing 75% of the sample. Approximately two thirds identified their ethnicity as White (n=10, 63%) and married (n= 10; 63%). Participants were predominately the parents of the adult with psychosis (n=12, 75%) (~~n=; 56%~~) and one third lived with the person they

cared for (n=5, 31%). Just over one third of participants were employed (n= 6 36%) or in retirement (n=6; 38%). Participants reported spending an average of thirty hours each week in contact with their relative with psychosis. In terms of the person living with psychosis, their mean age was 42 years (range 29 – 72 years) and the mean length of illness as reported by the carer was eighteen years (range=7 – 41 years). See Table 1 for sample characteristics.

[Insert Table 1 about here]

Themes

Analyses of interview transcripts identified five main themes comprising: (i) ubiquity of physical health problems in psychosis, (ii) gaps in service provision for those living with mental and physical health problems, (iii) carers' role in responding to service gaps, (iv) difficult conversations, (v) impact on carer health.

1. Ubiquity of physical health problems in psychosis

There was a broad range of physical health problems that carer participants had observed in their relatives with psychosis. The problems related to issues of diet, nutrition, obesity, sedentariness, hypertension, diabetes, cardiovascular conditions, and idiopathic pain. These were in addition to difficulties with oral hygiene, sexual health, and vision. Respiratory problems and cancer were also noted, albeit less frequently.

XXXX has developed diabetes as a result of putting on a lot of weight when she was taking clozapine, which she now takes metformin for. And uhm, she also has to take Statins as well, so this is ongoing.

I'd like to say she's improving her diet, but she finds it quite hard to control her diet. **Focus Group**

1, Participant 1, Mother

He's had heart palpitations twice in about 5 years, something like that? And since he went on the Clozapine a few years ago, about 2 or 3 years ago, he's put on some weight. Not major, but quite a lot for him, just round here [pointing to abdomen area]. **Focus Group 2, Participant 8, Mother**

It sort of knocked us for six when we found out she had breast cancer, couldn't believe it because she used to go every three years to have the, to have the scan done. **Interview, Participant 15, Husband**

Her teeth have been really gone and been shot, they're really bad. She's had to have lots and lots of extractions, and she has top and bottom plates, which she doesn't wear but they do make her look like she's got a whole mouth of teeth again. **Focus Group 1, Participant 3, Mother**

His eyes are very bad...he's got early macular degeneration. You don't usually get it until you're in your 60s and nobody knows why. **Focus Group 2, Participant 9, Mother**

Participants expressed finding it difficult to separate the physical health issues from the mental health difficulties, which they felt were inextricably linked and co dependant.

I think that from my perspective, his physical health is so closely linked to his mental state. When he's physically well, it means he's been mentally well enough to look after himself, to function and to go and be active and be out with his friends and do things. And when he's had a bad time mentally that shows very quickly physically, either in physical weight or the colour of his skin or the sparkle in his eyes that isn't there. **Focus Group 1, Participant 2, Brother**

It's all connected. It's like to me the needs, the different needs that person has are connected to mental and physical. It all comes as a package. You can't separate the two things. **Focus Group 2, Participant 10, Sister**

2. Gap between physical and mental health needs

Participants highlighted concerns and shared their personal disappointment over perceived gaps in service provision for their relatives with psychosis presenting with physical health difficulties.

My husband, doesn't only have mental health issues for a long time but the physical side, like with the cancer, he hasn't got enough support with any organization. Focus Group 2, Participant 11, Wife

When [my daughter] was ill; she has asthma and she needed a nebulizer and nobody on the ward at the [psychiatric hospital] knew how to set up a nebulizer. I mean that is really bad isn't it? If you've got someone with asthma needing a nebulizer and they [mental health staff] don't know how to set it up..... It's having an awareness of not just the mental illness of a person but....their physical needs. It's not just a mental illness. Focus Group 1, Participant 4, Mother

The mental health staff are good with his mental health but they're completely crap at remembering his dental appointments, for example. I don't expect necessarily everybody to have the same level of care I suppose for my son that I do, but I do get irritated when that sort of basic stuff you'd expect, doesn't happen. The essential ones like the dentist, the health check.... doesn't happen. Focus Group 1, Participant 5, Mother

It's about the physical aspect of the illness that mental health professionals don't have. They're starting to now. It's frustrated me for many years that the fact someone goes on Clozapine and blows up like a barge balloon and they say "oh no, don't worry about that, it's good for their mental health" what about their physical health? They say "well, we don't deal with that, we're mental health specialists" - to hell with that. Focus Group 2, Participant 12, Father

3. Responding to service gaps: carers as ‘general practitioners’

Participants described a complex and idiosyncratic physical health role that was tightly embedded within their main caregiving role. It comprised being the designated person to identify and, at times, diagnose physical health problems in their relatives and facilitate timely interventions from physical and mental health services, and their relative. The role also incorporated serving as an advocate.

I spend a lot of time on paper work. I spend a lot of time on the phone. I spend a lot of time talking to people. I spend a lot of time explaining to other people. **Focus Group 2, Participant 10, Sister**

My [son] missed his aerobics class on Tuesday because no one woke him up and because he’s on a roll, you don’t want that momentum to disappear. So I was on the phone saying “oh just ringing to check has he gone” “oh no, why not?”. “oh, I don’t think anyone woke him up”. And I’ll be angry with them. It shouldn’t be up to you, why isn’t it in the diary? So I went there and said to my [son] “do you want to go, do you want to go swimming”? And I went with him. **Focus Group 1, Participant 5, Mother**

I try to get his cholesterol checked after meetings and advice here. His GP told him that he didn’t need his cholesterol checked that’s he’s outside of the criteria, he’s too young, he’s fit and so he refused to do it. I wrote to the GP, still refused. So I don’t think he’s ever had his cholesterol checked. . **Focus Group 1, Participant 6, Mother**

Conversations about ‘its time you went to the dentist again’ and making sure she makes an appointment which she is not very good at doing. You normally have to make the appointments for her..making sure she keeps all her appointments. She’s not, she’s not very good, she forgets so she puts them somewhere and I put them in my diary to make sure she doesn’t forget. **Focus Group 2, Participant 13, Mother**

4. Difficult conversations

Participants described an ongoing and typically difficult process of trying to facilitate and maintain a dialogue with their relatives about physical health matters. The process and conversations required diplomacy and sensitivity from carers, alongside a heightened awareness about how their comments and approach impacted on their relative and/or were perceived by them. It was important for participants to avoid being perceived by their relative as ‘nagging’. Participants reported they had learnt over time, and often through a process of trial and error, the most effective strategies to use in their relationship to approach matters related to physical health issues.

Whenever I have said something, I have got to be careful, saying it in a civilised way... For me, it's a challenge for him to accept what I say is true, that it's good for him, that it's for his well-being and, most of the time when he's unwell he will probably just tell me to get lost because I'm trying to 'trick' him, but when he's well he'll say 'you're right, you're right, you're right.' ... I think it's very difficult. **Focus Group 2, Participant 10, Sister**

You don't want to be seen as in a nagging context because it disturbs your relationship with them if every time they come you know they're overweight and you're concerned about that and you've mentioned food again. You know they're not, you know they're not going to take much attention. So you don't want to keep on about it because it gets rather pointless and also it's a bit, it's a bit fed up making for both of you. **Focus Group 2, Participant 12, Father**

For many participants, their approach to avoiding difficulties or ruptures in their caregiving relationship over matters related to physical health involved enlisting the help of other people their relative liked or were indifferent to. The approach also involved making a deliberate decision to not discuss an issue.

So if I really want to get something through to him I speak about it with his support workers – “have you spoken about this... can you have a chat with him” because I know he’s going to be more open to listening rather than if it comes from me. **Focus Group 1, Participant 7, Mother**

I think in the parent role sometimes you’ve just got to accept that it ain’t going to be you. There has to be other people. I try to, I’ve got my sister who’s really helpful..... I just think on certain things that have been said from me I don’t care how skilled I’ve got to be it would just not be alright because it’s your mum and you know he doesn’t want to listen to that from you. But I know that he would be open talking to somebody else. **Focus Group 2, Participant 14, Mother**

It was noted however, that making a decision to avoid discussing what carers perceived to be an important and relevant issue, also left carers feeling uncomfortable and a sense of not doing enough.

It’s difficult because you’re wanting to maintain a relationship which you’ve not got any confrontational aspect to it, so that may lead you to a situation where sometime later you might feel somewhat guilty because you haven’t done a bit more about the porridge and the fruit or whatever it is that you are trying to encourage them to have. It leaves you in a sort of dilemma you know. **Focus Group 2, Participant 13, Mother**

Sometimes when I speak to him he loses sight that I’m coming from a position of love. So what happens is whatever I might say he then becomes defensive because he sees it as a criticism. I don’t know if I’m hitting a nerve or whatever, and it can escalate to the point I back off and I don’t take it further because I know it’s a sore subject. But in my mind I’m thinking it needs to be addressed and I’m unable to do that. **Interview, Participant 16, Father**

5. Impact on carer health

Carers described a process of how improvements and deterioration in their relative's physical health directly impacted on their own health and wellbeing. The impact included carer reports of feeling anxious about the future when they are no longer there to support.

[It's] anxiety making. I fear for the future. I want to try and maintain his health as long as I am alive, because I know what happens if he doesn't. If he keeps on putting on more weight, and more weight.....it seems like such a big issue going forward. I can see the future and I just don't want him to be going that way so that's where my anxiety comes from. **Focus Group 1, Participant 5, Mother**

It plays on my mind. I don't know if I'm overthinking or whatever. I'm thinking where it can go if he carries on eating. The things that he says he wants to do and I know that it can't happen if he's continuing the way he's eating and not looking after his physical health. **Interview, Participant 16, Father**

If I see him being active, getting to the right weight, looking after himself.... then that makes me happy. You see the result. You see an improvement. You see something positive and all the effort you put in is somehow going through that person. **Focus Group 2, Participant 10, Sister**

Discussion

This study sought to explore the subjective experiences of carers of adults with psychotic disorders who also have physical health problems. Data extracted from individual and group based interviews yielded five key themes. These reflected the ubiquity of physical health problems in psychosis; the gaps in mental and physical health service provision for individuals with psychosis; a carer's role in responding to service gaps and unmet need; the difficult conversations that carers have or seek to avoid with their relative over any matters related to their physical health, and the impact of patient physical health on carer health status and wellbeing.

The reports detailing the diverse physical health problems experienced by participants' relatives with psychosis were consistent with the wider literature on poor physical health functioning in severe mental health populations (Hayes, et al., 2017). Likewise, carers' reports of observing unhelpful and frustrating gaps in service provision for relatives with psychosis and physical health problems was consistent with current literature (Bindman et al 1997; Burns, Greenwood, Kendrick & Garlan, 2000) and served to reinforce ongoing initiatives to introduce parity in approaches to delivering optimal mental and physical health care (NICE, 2014; NHS England, 2016). We noted earlier that carers of people with psychosis can play an integral role in facilitating improved recovery outcomes, including provision of emotional and financial support, and advocacy (Lester, et al., 2011). The savings made by the government from the unpaid work of informal carers are estimated at 1.24 billion each year (Schizophrenia Commission, 2012). Our current findings extend this body of evidence to highlight carers' role in supporting their relative's physical health and the disappointment and frustrations commonly experienced when faced with gaps in service provision. The results indicated that carers were often required to or felt the need to step in and assume control of a situation to ensure their relative's physical health needs were met. They would try to compensate for the negative sequelae of the illness on their relative's thinking and behaviour (e.g. lack of motivation, disorganised thinking) that would present in parallel with gaps in service provision. Thus, for example, carers would escort a relative to a fitness class or provide regular wake up calls and reminders for attending scheduled physical health appointments. Participants could cite different examples of when they had not been involved or were unable to compensate for service gaps (i.e. a telephone reminder) and the negative effect it had on their relative's care. The current findings offer further support for the policy initiatives, and service and treatment guidelines seeking greater integration of physical and mental healthcare (NICE, 2014), and highlights gaps that can exist between recommended care and current practice (Das-Mushi, et al., 2016).

Many of the reports offered by carers had drawn direct links between the onset of physical health problems in their relative, specifically diet and weight gain issues, and commencement of anti-psychotic medication treatments. This would be consistent with the current literature that increased appetite and glucose tolerance can be known side-effects in some medications for some patients (De Hert, et al., 2011; Rummel-Kluge, et al., 2010).

Carers described links between their experiences of emotional dysfunction and a poorer state of their relative's physical health. They reported feeling anxious and frightened about the future, and over what would become of their relative.-They reported experiencing anxiety and fear about the future and what would become of their relative, were positive changes in their physical health profile not to occur. It is possible that participant anxiety (and other indices of emotional disturbance) is likely to be negatively affected by the broader focus within clinical and research settings on physical health issues in severe mental health and regular reports of reduced life expectancy in patients. That carers report high levels of emotional distress, is well established across different carer populations and illness phases (Gupta, Isherwood, Jones, & Van Impe, 2015; Poon, Harvey, Mackinnon, & Joubert, 2016); however, the specific links between anxiety and patient physical health problems is new and deserving of further exploration.

Though the study focused on patient physical health, it seems important to note that for most participants, physical and mental health was inextricably linked with a mutually dependent relationship. For carers, conversations about physical health would always (or should always) include conversations about their mental health. This view is also consistent with findings from interviews with a generic sample of mental health carers (Happell, et al., 2016).

Clinical implications

Though preliminary, the current findings offer important clinical implications. In support of previous calls (e.g. Cree, Brooks, Berzins, Fraser, Lovell, & Bee, 2015, Giacco, Dirik, Kaselionyte, & Priebe, 2017), healthcare professionals should aim to work in greater partnership with carers on physical health issues and acknowledge their role, perspective and contributions to optimising patient health outcomes.

In practical terms, it may be helpful for professionals to ask carers about the type of assistance they provide their relative with in addressing physical health issues, the resource implications and what support, if any, they may require or benefit from. Given the impact poor patient physical health may have on carer emotional functioning, carers might benefit from direct enquiry about concerns they have about patient health status and offered relevant support or signposting to services to address any negative emotional impact (e.g. anxiety) it may have on their functioning. Carers are having conversations about physical health with their relatives with psychosis and engaging in different supportive behaviours (e.g. providing reminders about appointments and accompanying them, responding to indicators of ill health; talking about nutrition and diet). These are conversations and behaviours which typically require careful navigation and ongoing awareness of and sensitivity to patient symptomatology and shifting presentation. They can also be difficult and impact on the rapport shared with their relative and quality of the caregiving relationship. Carers might benefit from opportunities to optimise their patient communication and engagement skills. This might be particularly beneficial for carers in the early illness phases, when the illness and its sequelae is new. Interventions to support carers' wellbeing and outcomes remain consistent with treatment recommendations for psychotic disorders (e.g. NICE, 2014).

Limitations

The sample, although diverse in the types of caring relationships represented was ~~made up of~~ predominately represented by parental carers ~~caregivers~~, which impacts the generalisability of the findings to other carer sub groups. While the predominance of parental carers, particularly mothers, remains a common picture in clinical and research settings (Onwumere, et al., 2017; Ruggeri, et al., 2017), the subjective experiences and related themes that might be argued to predominate in other carer groups (e.g. child carers, siblings, partners) ~~may~~ might have been overlooked. For example, we know that partner carers can often experience difficulties and confusion in distinguishing between caregiving and romantic partner roles, which may have implications in their experience of physical health difficulties in their partner (Jungabuer et al 2004). Although the results are informative and can be understood in the context of existing literature, the findings however, were derived from a small sample of only sixteen participants. Consequently, caution is required in the interpretation and wider generalisation of the findings. In addition, our recruitment pathways were limited to NHS funded carer support groups. It is possible, therefore, that participants might represent those most or least affected by their carer role, including areas related to patient physical health, and consequently their experiences may not reflect those of carers who were not attending support groups.

Whilst focus groups are regarded as a helpful methodology to initiate topic discussion and exchange of views in a group setting (Bryman, 2008), the more in-depth exploration of individual narratives will be missed. The current findings, however, were designed to offer an initial understanding of the issues experienced by carers and serve as a helpful start to undertaking further focused and hypothesis driven investigations. Given the diversity of perspectives on physical health issues in severe mental health (e.g. Gronholm, Onagbesan, & Gardner-Sood, 2017), the inclusion of the patient and health care professional perspectives (e.g. Lester, Tritter & Sorohan 2005) would have strengthened the study, enabled the triangulation of findings and more nuanced and broader clinical implications.

Conclusion

Though derived from a modest sample, our current findings highlight the issues about patient physical health and service provision reported by carers of people with psychosis. The findings also highlight the impact that carer concerns about patient physical health can have on carer wellbeing. The results speak to the importance of increasing greater awareness in physical and mental health staff of the different roles and expertise carers can have in supporting improved physical health outcomes for patient groups.

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